ADULT DAY CARE: ITS EFFECTS ON FAMILIES OF ELDERLY DISABLED MEMBERS*

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Study Highlights

1. Adult day care, more than family members or other community resources, was regarded by primary caregivers as their primary resource in helping them care for the disabled elderly person.
2. Services provided through adult day care were rated higher than services provided by family members or other community agencies in terms of quality, accessibility, availability, convenience, and reliability. In terms of cost, services from family and friends were rated higher.
3. Areas of family functioning most helped by adult day care included: having time for one's self, enjoying and being with other family members, attending to the needs of the older person, and keeping up with household chores.
4. Program activities, health services and facilities, and staff friendliness and caring were cited by primary caregivers as what they liked best about adult day care. Problems centering around transportation were cited as what they liked least about it. Specific recommendations for improving day care related to day care costs and the public funding of day care programs, the expansion of day care hours, and the publicizing of day care as a resource.
5. Participation in adult day care has helped the older person to function better, socially, emotionally, physically and intellectually.
6. Nevertheless, almost half the respondents indicated they anticipated having to place the older person in a long term care facility sometime in the

future, primarily for health reasons, the older person's or their own failing health.

7. The coping effects of day care were greatest for families under the most stress in terms of the severity of the older person's impairment, their financial status, the older person's gender, that is, male, and the gender distribution of the primary caregiver's children, that is, having more rather than fewer sons. Counseling services, adult day care as respite care, the alternative care grant, and the program's perceived helpfulness contributed to and enhanced the coping effects of the program.
8. County economic well-being, as measured by county tax filer median income, and county attitudes toward social programs, as measured by county tax filer expenditures for social programs, weakened some bivariate relationships and strengthened others. Of the two, the effects of county attitudes toward social programs were stronger and more pervasive on statistically significant relationships.

Adult Day Care: Its Effects on Families of Elderly Disabled Persons

The provision of community based services to enable families to care for elderly disabled members in their own home and thus prevent or forestall their out of home placement in an institution or other kind of long term care facility is a fairly recent policy development. It has emerged in part as a response to the spiraling cost of Medicare and Medicaid and in part to a heightened awareness that many older persons could remain in their own homes if supportive services were available to them in their communities to complement or supplement the services their families provide for them (Moroney, 1977). According to the Commissioner of the Minnesota Department of Public Welfare, 30 percent of persons entering nursing homes in Minnesota do not require extensive nursing home services (Furst, 1983).

One type of community based service that has emerged as an alternative to nursing home care is adult day care. Historically, adult day care is an outgrowth of psychiatric day hospitals to serve elderly mental patients first established in Russia in 1942 and Canada in 1946 (Dilworth-Anderson and Hildreth, 1982). In Great Britain and other countries, the concept came to embrace both psychiatric and non-psychiatric persons and included rehabilitative and supportive services of both a physical and psychosocial nature.

At the present time there are 30 adult day care programs in Minnesota, the first program having opened in Little Falls in the 1960s, illustrative of the recency of the history of such programs in this state ("Summary adult daycare survey," 1979). Each program functions under somewhat different structural arrangements, some being free standing and autonomous, others being affiliated with health care facilities of with community social

service agencies. Most are funded under Title III of the Older Americans Act or Title XX of the Social Security Act and charge a fee for service. Day care costs for persons eligible for both Medicaid and for nursing home care, as determined by a pre-admission screening team of the Department of Public Welfare in the county in which they reside, are covered by an alternative care grant. Services provided through the alternative care grant are federally reimbursable to the state through the Title XIX Medicaid waiver, a newly developed funding mechanism to facilitate the development of a variety of community and home based services for handicapped and elderly persons who otherwise would require out of home placement in an institution or other kind of long term care facility.

In general, adult day care is for persons 60 years and older who have a mental, physical, or social disability that impairs their functioning and socially isolates them. Most programs in Minnesota offer individual and family counseling, remotivation therapy, nursing care, diet and nutrition counseling, transportation to and from the program, and occupational therapy in the form of arts and crafts. Many programs in addition provide information and referral services, reality orientation, behavior modification, health education, recreational therapy, group counseling services, and activities of daily living (ADL). Although targeted at disabled older persons, from a systems perspective, such programs necessarily affect their families also. The questions this study sought to examine were: To what extent does adult day care help primary caretakers and their families cope with the care of the elderly disabled persons; what family and other resource variables serve to heighten or dampen its effects; and does its influence extend to families' present or future long term care plans for older members?

The dramatic increase in the numbers of persons 65 years and over, the prevalence of disability among persons in this age group, and the present context of cost containment in health care and social services' provision (Perlman and Giele, 1983), as manifested by the increased emphasis on family care of chronically ill and handicapped members, make these questions particularly relevant.

Theoretical Perspective and Literature Review

A basic assumption of the present study is that the care of an elderly disabled member is a stressful situation for families, particularly for family caretakers. Indeed, according to Hall, parent caring has become a source of considerable stress for many families (Hall, 1980), changing the nature and quality of family interactions and relationships, the ways in which family roles are defined, allocated and enacted, and the boundaries of family life. Moroney (1983) found that families of disabled members are more likely than other families to experience physical strain and fatigue as well as financial burden, stigma, sleep interruption, social isolation and lack of time for performing necessary household tasks or engaging in social and recreational activities. Their situation may be further compounded by other stressful family life events (Holmes and Rahe, 1967), such as the unemployment or death of a family member, loss of income, the serious illness or the failing health of the primary caretaker or other family members. The accumulation of such stressors has been aptly termed "stress-pile-up" (McCubbin and Patterson, 1981), a situation that adversely affects families' coping capacities, placing demands on them that often exceed their needs-meeting resources or that overwhelm their capacities for drawing effectively on those available to them,

depending in part on how they define and interpret their situation. Such definitions and interpretations reflect their unique family history, their values, and present circumstances and resources. Internally, such resources, insofar as the present study is concerned, pertain to family size, structure, and composition; family life cycle stage, including the ages of the primary caretaker, the older person, and oldest and youngest family members; and socioeconomic and health status.

With respect to family structure and composition, for example, Cantor (1981) found that the spouse if living, and living with the older person is the person's major resource and source of help. Along this same vein, Treas (1977) asserts that older couples, when confronted with infirmities, can maintain considerable independence by taking care of each other and reallocating household chores. When a spouse is not present, adult daughters provide the greatest amount of help (Shanas, 1974; Sussman, 1976), although married daughters provide less help than unmarried daughters, regardless of whether or not they have children in the home (Stoller, 1983). This is not the case for adult sons, however, whom Stoller found to provide more help to parents if they have children under 6 in the home. Stoller interprets this finding to suggest that adult sons transfer their parent-caring responsibilities to their wives during this early stage of their family life. Indeed, in-laws have been found to be a more important family resource than previously thought.

With respect to family life cycle stage and daughters, Stoller points out that although many scholars have expressed concern about the ability of younger daughters to cope with parent-caring in addition to the competing demands of employment, marriage, domestic production, and family, particularly when the latter includes the care of young children, few have attended to the problems

of older adult daughters. Parent-caring, she suggests, may be more burdensome for older than younger daughters because many may be entering old age themselves, and hence may be confronted with having to meet the emotional and physical demands inherent in parent-caring with depleted emotional and physical energies. Also, faced with the possible irreversibility of their parent(s) declining health and functioning, some may experience anticipatory bereavement, not only for the loss of their parents, but also for the loss of themselves as they once were and indeed, may become.

In addition to age and family life cycle stage, family composition and structure, Cicerelli (1981) found socio-economic status to be a relevant factor in the parent-caring adult children provide. He found that adult children of lower socio-economic status provided more help to parents than children of higher socio-economic status. The latter not only were more apt to be geographically separated from their parents, but they also were more apt to purchase rather than provide the services their parents need directly themselves.

External family resources pertain to a variety of community services that families may use to help them cope with stressful family situations. The use of community resources by families of elderly disabled persons seems to be related to the degree of the older person's impairment and consequent demands on family time and energy. Giele (1984) found in her analysis of 1976 Survey of Income and Education conducted by the Census Bureau that the use of outside supports not only was associated with the older person's level of impairment, but also with household type. Families headed by females were three to four times more likely to receive help from outside resources than those headed by both a male and female. Similarly families with a severely or moderately handicapped member were significantly more likely to receive outside support than those with a mildly handicapped member.

That adult day care may be a resource for families as well as for elderly persons and offer a viable alternative to institutionalization is empirically supported by existing studies. McCuan (1976) found, for example, that in addition to supporting the physical maintenance of elderly persons, adult day care also supports the psychological functioning of their families. Similar findings emerged from a study of adult day care in the Chicago area conducted by Dilworth-Anderson and Hildreth (1982) who found the counseling services and social activities it incorporated to be important resources for families as were the day care staff themselves, who telephoned the families frequently thereby strengthening their relationship to them. One conclusion reached by researchers of one alternative care study is that family functioning is likely to be strengthened rather than weakened by such programs because they divert and reduce the demands of parent caring on families (Sanders and Seelbach, 1981). An experimental study of three alternative health care services designed to delay or prevent institutionalization of elderly members, one of which was adult day care, revealed that with the exception of great or extreme disability, the psychological, social, and economic costs of family and community care are much less than institutional care (Montgomery, 1982). One study examining the differentiated use of health services among elderly disabled persons found that use of services was related to their availability (Wan and Arling, 1983) which in turn reflects the larger environment in which older persons and their families live. As Eulau and Prewitt (1973) note, "The unit is not set off from its environment, but is a part of it." The relationship of families to their environment may be instrumental in terms of mutual role expectations with respect to the care of elderly disabled members, for example, or it may be cultural in terms of

shared norms and attitudes with respect to the collective provision of community resources, such as adult day care and other services.

Thus, to answer the study's questions, what are the coping effects of adult day care on families of older disabled persons and do these effects extend to families' long term care plans for them, the following variables were examined: families' functioning and coping capacities before and after day care; the multiplicity of stressors or "stress pile-up" that families may be experiencing; family resources, both internal and external, that families have available to them; families' perceptions and assessments of these resources; and the economic and political environment of the communities in which families live, the latter providing the context and conditions for the development of external resources upon which families may draw to help them cope with stressful family situations. Major hypotheses of the study were that the coping effects of day care would be greater for families under greater stress and for families who have fewer internal and other external resources available to them.

Measuring the Variables

Dependent variables

Several measures were used to assess the coping effects of adult day care as a resource for families with elderly disabled members, the study's major dependent variable, each focusing on slightly different aspects. One measure pertained to the ways in which and the extent to which the program enables families to cope and function, socially, psychologically, and financially. Specific coping dimensions included the primary caretakers' and

their families' ability to: 1) keep up with household chores; 2) purchase goods or services needed; 3) work outside the home; 4) do things together as a family; 5) enjoy each other's company as a family; 6) engage in hobbies enjoyed at home; 7) engage in leisure time activities outside the home; 8) be with friends occasionally; 9) attend church or synagogue; 10) attend to the needs of the elderly disabled person; 11) attend to their own individual needs; and 12) attend to the needs of other family members. Responses were ordinally scaled from 1 to 5, 1 being to absolutely no extent and 5 being to a very great extent. Change in family functioning and coping as a consequence of adult day care, a second measure of the program's coping effects, was determined by responses to questions asking about the same coping dimensions conceptualized in before and after day care terms. Scaling was identical to the previous set of coping and functioning items.

A third measure of the program's coping effects was a single question that pertained to the degree to which the program was perceived by caretakers as being helpful to them and their families. To measure and ascertain families' plans for the long term care of the elderly disabled member, both present and future, the two remaining dependent variables, a nominal level yes-no question was asked regarding families' present plans for placing the older person in a long term care facility, while an ordinally scaled yes, depends, and no question was asked with respect to their future plans in this regard.

Independent variables: Internal family resources--family size, structure, composition, life cycle stage, and religious and ethnic background--and external resources.

Several questions were used to measure internal family resources. Family size, structure, and composition were measured by questions asking about the respondents' marital status with 5 coded response possibilities: 1) married, 2) remarried, 3) divorced or separated, 4) widowed, and 5) never married; about the number of children in the family and their gender; the number of children, relatives and non-relatives living in the home; the number of family members living within a half hour's drive; and the relationship of the primary caretaker to the older person. Family socio-economic status was measured by questions dealing with the primary caretakers' employment status, educational background, and annual family income. Response categories for employment status included: 1) full time, 2) part time, and 3) unemployed. Categories of response for educational background were: 1) less than high school, 2) high school, 3) some college, 4) college graduate, and 5) post graduate education. For family income, response categories ranged from less than $5,000 up to $30,000 in $5,000 increments and then in $10,000 increments up to $50,000 and over. To measure their ethnic and religious background, respondents were asked to indicate whether they were white, black, Native American or Hispanic or of some other ethnic origin, and whether they were Protestant, Catholic or Jewish, or of some other religious faith.

Family life cycle stage was measured in terms of primary caretaker's age and ages of oldest and youngest child. To determine the member who in addition to the primary caretaker assumed the most responsibility for the care of the older person, and who assumed the least responsibility,

respondents were asked to designate who such members were, spouse, daughters, sons, brothers, sisters, and so forth. The ordinal position of these members was determined by asking respondents yes or no, whether the member who assumed most responsibility was the oldest child in the family, and similarly whether the member who assumed least responsibility was the youngest member in the family.

Another series of questions measuring family supports or resources pertained to the extent of help primary caretakers perceived they receive in caring for the older disabled person from family members, such as spouse, adult children, siblings, other relatives and friends; and community agencies, such as the church or synagogue, adult day care center, public health center, mental health center, and county welfare department. Responses were ordinally scaled from 1 to 5, 1 being to no extent, and 5 to a very great extent.

To measure their assessment and evaluation of the services they receive from such resources, that is, from family members, community agencies, and day care in particular, respondents were asked to rate each in terms of: 1) quality, 2) availability, 3) accessibility, 4) convenience, 5) reliability, and 6) cost. Again, coded responses were ordinally scaled from 1 to 5, 1 being very poor and 5 being excellent. Specific questions regarding the use and helpfulness of counseling services and respite care were asked to obtain measures of these particular services as resources to the study's families.

Specific questions with respect to adult day care as a resource also were included. Such questions had to do with the length of time, measured in number of months, the older person has participated in the program, the

number of days per week he or she attends, and the auspices of the program, that is whether public, sectarian, or non-sectarian-private. In addition, the means by which families learned about the program was determined by asking who told them about it. Coded responses included social worker, friend, family member, families of other participants, doctor, clergy, or news article, but provision was made for other responses as well.

Intervening stressor variables: Health status of primary caretaker and other family members, functioning capacity of older persons, stressful family life events, and day care costs.

Health status of the primary caretaker was measured by asking the respondent to indicate whether his or her health was: 1) very poor, 2) poor, 3) fair, 4) good, or 5) excellent, and if less than good, the extent to which his or her health affected his or her capacity to care for the older disabled person. The health of other family members for whom the caretaker was responsible was similarly measured, except that if it was reported to be less than good, a series of questions was asked to determine the ways in which and the extent to which the person's functioning was affected in identified areas. Specific functioning items pertained to the person's ability to see, walk, talk, hear, feed self, toilet self, relate to and communicate with people, and understand what was being said to him or her. These questions were ordinally scaled from 1 to 5, 1 being to no extent and 5 to a very great extent. A similar set of functioning questions was asked and similarly scaled with respect to the older disabled person. In addition, the length of time the older person has been incapacitated was determined to measure the over time duration of the primary caretaker's caretaking responsibility for him or her.

Stress resulting from recent family life events, that is, stressors in addition to the care of the older disabled person, was measured by asking the extent to which any of the following events had been a source of stress for primary caretakers and their family during the past year: 1) the death of a family member, 2) the serious illness of a family member, 3) the loss of a job, 4) a divorce or separation of family member, 5) the addition of a new family member through birth, 6) adoption, 7) marriage or 8) remarriage, 9) a job change, 10) a serious disability, 11) a large loss of income, 12) a large increase in income, 12) difficulty with the law, and/or 13) the institutionalization of a family member. This set of questions was followed by another that attempted to determine the extent to which such stressors affected respondent's and their families' coping and functioning capacities, using the same items used to measure the program's coping effects on families. Another stressor measure pertained to the extent to which families experienced difficulty in meeting the costs of day care. Again, responses to all of the above items were ordinally scaled from 1 to 5, 1 being to no extent and 5 to a very great extent.

Exogenous Environmental Variables

Environmental variables, such as the size and economic well being of the county in which families with older persons in the adult day care programs reside, were measured by county population in 1981 and tax filer median income in each of the three counties in 1981. Community attitudes toward collective social provision were measured by per tax filer expenditures for social services in each of the counties in 1981.

Design and Methodology

To obtain the foregoing information, a telephone survey was conducted of a purposive sample of primary caretakers of elderly persons participating in 3 different adult day care programs in 3 different counties in the 7 county metropolitan area in Minnesota, Carver, Hennepin and Ramsey. Adult Day Care Program 1 (ADCI), is a publicly sponsored program in Carver county; Carver county has a population of a little more than 39,000 persons, a tax filer median income of $9,593 and a per tax filer expenditure of $25.07 for social service programs for 1981. Adult Day Care Program 2 (ADC2), is a non-sectarian, not-for-profit, privately sponsored program in Ramsey county; Ramsey county has the second largest population in the state, almost a half a million persons, a tax filer median income of $12,493, and a per tax filer expenditure of $31.28 for social service programs for 1981. Adult Day Care Program 3 (ADC3), is a not-for-profit sectarian sponsored program in Hennepin county; Hennepin county has the largest population in the state, almost a million persons, a tax filer median income of $13,801, and a tax filer expenditure of $27.12 for social service programs for 1981. Thus, the county in which ADC3 is located has a higher per tax filer median income than the county in which ADC2 is located, but spent less per tax filer on social service programs in 1981 than ADC2.

Sample selection was carried out by the directors of each of the 3 programs. Only families of older persons having a primary caretaker were selected to participate in the study, 29 from ADCI, 37 from ADC2, and 28 from ADC3. Each of the directors sent a letter to prospective participants informing them of the study and encouraging their participation in it (see Appendix A). In addition, they called each of the families to obtain their permission to release their names and phone numbers to the researcher in

conformity with norms of confidentiality and laws governing data privacy. At the same time they also informed families of their right to refuse to participate in the study, assuring them that the program status of the older person in the adult day care program would not be jeopardized should they prefer not to participate. Thus, participants were well prepared for the research prior to their actual involvement in it.

In all, 82 primary caretakers participated in the survey, representing a remarkably high response rate of 87%. Three of the caretakers were responsible for the care of 2 elderly parents, all of whom attended ADC1, bringing the number of disabled older persons on whom information was obtained to 85. Of the 12 primary caretakers who did not participate in the study, 8 declined when contacted because of lack of interest, 2 could not be reached after several attempts, 1 was out of town, and 1 declined because his wife was being hospitalized. In terms of each of the 3 programs, 3 or roughly 10% of the non-participants were from ADC1, 6 or about 16% were from ADC2, and 3 or 10% were from ADC3. With respect to ADC2, the higher non-participation rate can be explained by the fact that primary caretakers in this group were not contacted until after the first of December with the last contacts not being made until 7 to 10 days before Christmas. This timing, though unfortunate, was unavoidable because of constraints operating on ADC2 that prevented interviews from taking place with primary caretakers in this group before December 5. Still the large response rate both overall and for each of the 3 groups indicates that responses are representative of the families of older persons participating in the 3 adult day care programs overall and in each of the 3 programs. It also attests to the interest of the families in their older member, the program he or she attends, and the research.

A pre-tested, precoded structured questionnaire with 173 items, many of which were taken from an earlier study conducted by the primary investigator with respect to families of mentally handicapped children, was developed to conduct the survey (see Appendix B). Six open ended questions giving participants an opportunity to express themselves in their own words and style were included at the end of the questionnaire both to allow for response flexibility and also to obtain reliability and validity checks on earlier responses. Such questions pertained to what respondents liked best and least about the program, how adult day care has affected their relationship to the older family member and to other family members, and how it may have affected their feelings toward the older person. Comments and suggestions concerning the program were invited in a final open ended question.

Two interviewers were hired to conduct the survey; both had prior experience in working with people in a professional capacity, one of whom had specialized interviewing experience as an intake worker in a counseling center. A training session was scheduled to familiarize the interviewers with the study, the questionnaire, and adult day care. To make sure they understood the questions in the form they were written and the terms used, and also to assure proper coding of responses, each interviewer was given an opportunity to conduct a practice interview. In addition, written instructions were provided outlining the nature of the study, explaining adult day care, the manner in which the interviews were to be conducted and the coding of questionnaire items, with the various phone numbers of the primary investigator listed in the event unanticipated problems or questions arose during the conduct of the survey (see Appendix C). After the first few interviews when questions with respect to coding did arise, the process

proceeded smoothly. An oral consent form whose essence the interviewers were instructed to follow before proceeding with the interviews also was provided (see Appendix D). Interviews took approximately one half hour to an hour to complete; all interviews were completed within a period of 10 weeks.

In the meantime, information pertaining to environmental variables concerning county population was obtained from the state demographers office; information pertaining to tax filer median income and expenditures for social service programs for 1981 was obtained from the Minnesota Department of Public Welfare. Information pertaining to program variables such as the number of days the older person participates in adult day care and length of time of his or her participation was obtained from records of the 3 adult day care programs through the program directors.

Data analysis

Percentages and means were used to examine response differences on the several rating scale items; open ended responses were content analyzed. Pearson's r, supplemented by Eta^2, was used to examine the relationship between the dependent variables and the study's several independent and intervening variables. In addition, two sample t tests were performed on the placement plans of families relative to variables initial analysis suggested might be operative, as was analysis of variance with respect to the environmental variables. Partial correlational analysis also was undertaken to control for the effects of the environmental variables on statistically significant bivariate relationships.

To facilitate the data analysis, several sets of related items were summed and averaged to obtain indices. For example, a functioning score

was obtained in this manner for both the elderly person and other family members with a handicapping condition. A second functioning score for the older person representing perceived improvement in the older person's functioning in 4 cited areas as a result of adult day care, was similarly obtained. A similar procedure was used to obtain a family life events stress score for the 13 listed events previously cited. Three family functioning and coping scores likewise were obtained on the 12 coping dimensions measured in the study for both before and after the older person was in adult day care and following recent stressful family life events. The latter was labeled coping 1, the after adult day care measurements were labeled coping 2, and the before adult day care measurements were labeled coping 3. To obtain a change score in family functioning and coping that could be attributed to adult day care, coping score 3 was subtracted from coping score 2.

A community resource score also was obtained by adding and averaging respondents' ratings on the extent to which they received or used 8 identified community resources, in addition to adult day care, in helping them care for the elderly person. A total family resource score was obtained on the extent to which respondents receive help from 11 informal and formal sources comprised of both family and community resources. Evaluation scores were obtained for services received from adult day care, from family and friends, and from community agencies by similarly adding and averaging respondent ratings for each on the 6 established service criteria.

The study's variables and composite indices represent a mix of ordinal and interval level measurements. Some interval level measurements, such as age and income, included unequal intervals which could be

problematic in some studies but were not so considered in this study since the attempt was to obtain an ordinal ranking of these variables rather than their precise measurements.

The Study's Findings

Internal family resources: marital status, family composition, socio-economic status, and ethnic and religious background.

Who were the primary caretakers of the older persons participating in the adult day care programs included in the study? Similar to the studies cited earlier, they generally were spouses, 39% (N=33), of whom 33% (N=28) were wives and 6% (N=5) husbands, or adult children, 52% (N=44), of whom 37% (N=31) were daughters and 15% (N=13) sons (see Table 1). However, with respect to sons, it was their wives rather than the sons themselves who for the most part responded as the older person's primary caretaker, a granddaughter-in-law so responding in one instance. Other primary caretakers included parents in two cases, a sister, a sister-in-law, and other relatives, such as a great niece. Clearly, the caretaking role in the families surveyed has been allocated primarily to the wives, daughters, daughter-in-laws, sisters, sisters-in-law, and other female relatives.

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Insert Table 1 about here

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The ages of primary caretakers ranged from 27 to 82 years, their average mean age being 54 years; a little over one-fourth were 65 years of age and over. For the most part, they were married, 85% (N=72) of whom only 2% (N=2)

Table 1. Relationship of Primary Caretaker to Older Person

Relationship	n	%
Wife	28	33
Husband	5	6
Daughter	31	37
Son or daughter-in-law	13	15
Sister	1	1
Brother or brother-in-law	1	1
Parent	2	2
Other relatives	4	5

* Percentages may be greater or less than 100 because of rounding.

were remarried while only 8% (N=7) were single never married. Among the remaining 7% (N=6) who previously had been married, only 5% (N=4) were divorced or separated and 2% (N=2) were widowed (see Table 2).

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Insert Table 2 about here

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The number of children per caretaker ranged from none, 14% (N=12) to 8, 3% (N=3), the modal number being 3 (N=24), but most, 56% (N=45), no longer had any children living at home. For those who still did, none had more than 4 at home (N=1) while 15 (18%) had 1 child, 15 (18%) had two children and 6 (7%) had three children at home. In addition, 15% (N=13) indicated relatives other than children or parents lived in the home with them; only 3% (N=3) reported having a non-relative living with them.

Most of the children of the primary caretakers were sons, the modal number being 1 (N=27), but 69% (N=59) had 1, 2, or 3 sons; one primary caretaker reported having as many as 7 and 2 as many as 6 sons. In contrast to the 19% (N=16) who reported having no sons, about 30% (N=25) reported having no daughters. Sixty-six percent of the primary caretakers reported having 1, 2, or 3 daughters which is similar to the percentage reporting having that number of sons. None of the respondents, however, had more than 4 daughters (N=2). Ages of the oldest child ranged from 1 to 53, the average mean age for oldest child being 29 years. Ages of youngest child ranged from 1 to 50 years, the average mean age for youngest child being 20 years.

Whereas males outnumbered females as children, 144 sons to 109 daughters, the opposite was true for siblings, sisters outnumbering brothers

Table 2. Marital Status of Primary Caretaker

	n	%
Married	70	83
Remarried	2	2
Divorced/Separated	4	5
Widowed	2	2
Never Married	7	8

* Percentages may be greater or less than 100 because of rounding.

by 19, 122 sisters to 103 brothers. The modal number of both brothers and sisters was 1, but for brothers, this number represented 32% (N=27) of the study's respondents whereas for sisters, it represented only 26% (N=22) (see Table 3). The percentage having no brothers or sisters was the same, 34% (N=29), as was the percentage reporting having 2 sisters and 2 brothers, 20% (N=17) for each. However, the number reporting having 3 sisters outnumbered those reporting having 3 brothers by 6, 10 respondents indicating they had 3 sisters and only 4 indicating they had 3 brothers. One primary caretaker reported having as many as 8 sisters, and 2 as many as 7 brothers.

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Insert Table 3 about here

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Clearly, the overwhelming majority of primary caretakers, 66%, had at least 1 or more siblings with whom to share caretaking responsibilities, and almost all, 84% had 1 or more relatives who lived within a half hour's drive from their home. As a matter of fact, one primary caretaker reported having 40 family members who lived a half hour away, although the average number was 5. Sixteen percent (N=14) reported having no family member living close by.

When asked to indicate who in the family in addition to themselves assumed the <u>most</u> responsibility for the older person in adult day care, 20% (N=17) identified their spouse, 21% (N=18) their daughter, and 9% (N=8) their son (see Table 4). Fully one-fourth (N=21) did not identify

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Insert Table 4 about here

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Table 3. Number of Family Members as Potential Resources to Primary Caretakers

Number of Family Members as Potential Resources	Sons		Daughters		Sisters		Brothers	
	n	%	n	%	n	%	n	%
0	16	19	25	29	29	34	29	34
1	27	32	22	26	22	26	27	32
2	18	21	23	27	17	20	17	20
3	14	16	11	13	10	12	4	5
4	5	6	2	2	3	4	3	4
5	---	---	---	---	2	2	1	1
6	2	2	---	---	1	1	2	2
7	1	1	---	---	---	---	2	2
8	---	---	---	---	1	1	---	---
No Response	2	2	2	2	---	---	---	---

*Percentages may be greater or less than 100 because of rounding.

Table 4. Family Member Most and Least Responsible for Helping Primary Caretaker in Caring for Older Person

Family Member	Most Responsible		Least Responsible	
	n	%*	n	%
No one	21	25	18	21
Wife**	1	1	-------	
Husband	17	20	3	4
Daughter	18	21	8	9
Son or daughter-in-law	8	9	21	25
Sister	9	11	7	8
Brother or sister-in-law	3	4	16	19
Parent	2	2	-------	
Other relatives	1	1	-------	
No response	5	6	12	14

* Percentages may be less or more than 100 because of rounding.

** Most respondents were women which accounts for the single response in this category.

anyone, just as one-fifth (N=18) did not identify anyone in the family as being least responsible, but if sons and brothers were less frequently identified as being the most responsible, 13% (N=11), they were the most frequently identified as being the least responsible, 44% (N=37). In terms of the caretaking role and ordinal family position, only 20% (N=17) indicated the most responsible were oldest children; about the same percentage, 19%, indicated the least responsible were youngest children. Thus, it would appear that responsibility for helping with the caretaking role is not necessarily related to being the youngest or oldest in the family, as might have been assumed, although it clearly is related to gender.

Although most of the respondents were not employed outside the home, 47% (N=40) were, 31% of whom worked full time and 16% part time. Educationally, only 12% (N=10) had not completed high school. Twenty percent were college graduates, 6% of whom had done some post graduate work, while an additional one-fourth, 27% (N=23), had some college education. With respect to income, only 1 primary caretaker reported an annual family income of less than $5,000, 6 having incomes of $50,000 and over. Overall average income for the families was between $15,000 and $20,000, 14% (N=12). The modal income, however, was $5,000 less per year than the average, $10,000 to $15,000 (N=16). With respect to ethnic background, almost all were white, 94% (N=80), with only 3 blacks, 1 native American and 1 Hispanic represented in the group. With respect to religion, two-thirds, 65% (N=55), were Protestant, and one third were Catholic, 31% (N=26); only 2 were Jewish, with 2 not indicating a religious preference.

The disabled older person

With respect to the living arrangements of the older person him or herself, most lived with their spouse, 41% (N=35) or adult children, 34% (N=29) or both spouse and children, 4% (N=3), comprising 79% of the older persons in the group. Only 14% (N=12) lived alone, while the remaining 7% lived with other relatives (N=6) or non-relative (N=1) (see Table 5). Of those living with adult children, 25% lived with a daughter while only 9% lived with a son, highlighting again the gender pattern in family caretaking.

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Insert Table 5 about here

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Ages of the older disabled person ranged from 47 to 94 years, the median age for the group as a whole being 77, 63% (N=54) being 75 and over, 6% of whom were 90 to 94. Uncharacteristically for older persons as a group, males outnumbered females in the present study by one. In all, there were 43 males and 42 females represented among the older disabled persons in the study.

Three-fourths (N=63) had been disabled for more than 2 years, some for as long as 20 or more years, and for one person, since birth, 65 years ago. Most affected by their disability was their ability to walk ($\bar{x}$=3.0, s.d.=1.2), to communicate with others ($\bar{x}$=2.8, s.d.=1.2), and relate to others ($\bar{x}$=2.8, s.d.=1.2). Such averages, however, obscure the fact that 70% (N=60) of these older persons had difficulty walking to some, a great, or very great extent, that 61% (N=52) similarly had diffi-

Table 5. Living Arrangement of Older Person

	n	%
Lives alone	12	14
With spouse	35	41
With adult daughter	21	25
With adult son	8	9
With spouse and children	3	4
With other relatives	5	6
With non-relatives	1	1

*Percentages may be greater or less than 100 because of rounding.

culty communicating with others, 57% (N=49) in relating to others, 49% (N=41) in talking, and 46% (N=39) in understanding others (see Table 6). Such functional impairment reflects the high prevalence of Parkinson's and Altzheimer's diseases among the older persons in this group, as well as the prevalence of other cognitive disorders and health problems, such as arteriosclerosis, depression, arthritis, diabetes, and heart disease. Although fewer persons suffered from an inability to see and hear to some, a great, or very great extent, the percentages nonetheless are substantial for those who did, 42% (N=36) and 32% (N=27) respectively. Over one-fifth, 22% (N=24), also found it difficult to toilet themselves.

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Insert Table 6 about here

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On the average, the older persons participated in adult day care 2 1/2 days per week, 12 participating only 1 day and 8, five days, modal participation being 2 days per week. On the average, they had attended adult day care for about 2 years, 23 months to be exact, but 20% (N=16) had attended day care for as little as 1 month while 36% (N=31) had attended for 2 years or more. Primary linkage sources leading to their participation in the program included social workers (N=24), doctors (N=11) other family members and nurses (N=10 each), friends (N=8), other social programs (N=4), and such formally designated linkage sources as outreach workers and First Call for Help (N=2). Other access means were more random and serendipitous reflecting the ingenuity of the primary caretakers themselves rather than the planful design of the service system itself. Such access measures included a telephone directory search, "calling around," and happenstance conversations with persons in face-to-face relation-

Table 6. Extent to Which Disability Affects Older Person's Functioning

Affected Areas of Functioning	No/Small Extent		Some Extent		Great/ Very Great Extent	
	n	%*	n	%	n	%
Walking	25	29	23	27	37	43
Relating to others	36	42	24	28	25	29
Communicating	33	39	27	32	25	29
Understanding	46	54	17	20	22	26
Talking	44	52	21	25	20	24
Seeing	49	58	20	24	16	18
Toileting self	61	72	12	14	12	14
Hearing	58	69	18	21	9	11
Feeding self	71	84	11	13	3	4

* Percentages may be greater or less than 100 because of rounding.

ships, such as a customer and a neighbor, the differentiating the latter respondent from a friend. Clearly, multiple sources of linkage are necessary for families to obtain needed services for their members, both formal and informal.

Other potential stressors: health status of other family members and the primary caretaker, and recent family life events.

Only 9% (N=5) of the primary caretakers indicated that the health status of other family members for whom they were responsible was less than good, indeed, very poor to only fair. Functioning abilities most affected to some, a great, or very great extent included communicating with others, N=4, walking, N=4, and relating to others, N=3. The capacity for self-feeding and seeing was a problem for 2 and self-toileting, a problem for 1.

Primary caretakers reported that they themselves were in good to excellent health, 83% (N=71). For those reporting their health was less than good, 17% (N=14), 11% (N=9) said it was only fair, while 6% (N=5) said it was poor or very poor. Thirteen percent, (N=11), also indicated their health affected their ability to care for the disabled older person, but only to some or a small extent.

Family life events that were a source of stress for primary caretakers and their families to at least some or greater extent during this past year included: 1) a serious disability of a family member, 43% (N=36); 2) a serious illness of a family member, 37% (N=31); 3) the death of a family member, 30% (N=26); 4) loss of income, 12% (N=10); 5) loss of a job, 11% (N=9); and 6) a job change, 5% (N=5). Less frequently occurring

stressful family life events included the addition of new family members through birth, 4% (N=3), marriage, (N=2), and adoption (N=1); and the institutionalization of a family member (N=3). Divorce and separation were not among the family life events experienced by families in this study, nor was difficulty with the law (see Table 7). Clearly, health more than income and income more than family structural events were the primary sources of stress for primary caretakers and their families in the present study, a finding not too surprising, given the study's focus.

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Insert Table 7 about here

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Family functioning and coping as a consequence of stressful family life events and before and after adult day care.

Areas of family functioning and coping most affected by family life events to some, a great, or very great extent, in order of descending frequency included: 1) engaging in leisure time activities outside the home, 53% (N=45); 2) doing things together as a family, 45% (N=38); 3) attending to one's own needs, 40% (N=34); 4) enjoying each other's company as a family, 38% (N=32); 5) being with friends occasionally, 37% (N=31); 6) keeping up with household chores, 36% (N=30); 7) engaging in hobbies at home, 34% (N=28); and 8) purchasing needed goods and services, 31% (N=26). At least 20 percent or more reported that stressful family life events similarly affected their ability to attend to the needs of the older disabled person, 23% (N=21); attend church, 23% (N=21); and attend to the needs of other family members, 21% (N=17), while only 14%

Table 7. Extent of Occurrence of Stressful Life Events in Past Year

Family Life Events	No/Small Extent n	No/Small Extent %*	Some Extent n	Some Extent %	Great/ Very Great Extent n	Great/ Very Great Extent %	No Response n	No Response %
Illness	13	15	5	6	26	31	41	48
Disability	12	14	17	20	19	23	37	44
Death	7	9	6	7	20	23	52	61
Income loss	5	6	4	5	6	7	70	82
Job loss	6	8	5	6	4	5	70	82
Job change	13	17	2	2	3	3	67	79
Marriage	13	16	------		2	2	70	82
Adoption	4	5	------		1	1	80	94
Institutionalization of a family member	3	3	2	2	1	1	79	93
Birth	19	22	3	4	------		63	74
Income increase	3	3	2	2	1	1	79	83
Separation/divorce	2	2	------		------		83	98
Problem with law	3	3	------		------		82	97

* Percentages may be more or less than 100 because of rounding.

(N=11) so reported with respect to working outside the home (see Table 8). Clearly, time for one's self and family were the primary areas of family functioning most affected by stressful family life events experienced by primary caretakers and their families this past year.

Areas of family functioning and coping most helped by the older person's participation in adult day care to some, a great, or very great extent in order of descending frequency include: 1) attending to the older person's needs, 83% (N=70); 2) attending to one's own needs, 72% (N=62); 3) keeping up with household chores, 64% (N=54), 4) enjoying each other as a family, 60% (N=51), 5) doing things with each other as a family, 54% (N=45); 6) purchasing needed goods and services, 52% (N=44); 7) engaging in activities outside the home and being with friends occasionally, 49% each (N=42); 8) engaging in hobbies at home, 44% (N=37); and 9) attending to the needs of other family members, 38% (N=32). As can be seen in Table 8, areas of family functioning least affected by the older person's participation in adult day care to some, a great, or very great extent include working outside the home, 27% (N=22), and attending church, 15% (N=12). Clearly among areas of family functioning most helped by adult day care were those most affected by stressful family life events, time for one's own self, for enjoying and being with family, for attending to the needs of the older member, and taking care of household chores.

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Insert Table 8 about here

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The above findings are best illustrated by comments to open ended questions asking primary caretakers what they liked best and least about

Table 8. Family Functioning and Coping: Extent to which Affected by Stressful Family Life Events, Extent to which ADC* has Facilitated, Extent to which Family Coped before ADC, to Some, Great and Very Great Extent (N=85)**

Family Functioning	Following Stressful Family Life Events		Facilitated by ADC		Before ADC	
	n	%	n	%	n	%
Attend to older person's needs	21	23	70	83	78	92
Attend to own needs	34	40	62	72	64	75
Do household chores	30	36	54	64	62	73
Enjoy family	32	38	51	60	56	66
Do things with family	38	45	45	54	56	66
Make needed purchases	26	31	44	52	63	74
Recreation/outside home	45	53	42	49	47	56
Be with friends	31	37	42	49	47	56
Hobbies at home	28	34	37	44	44	52
Other family member's needs	17	21	32	38	45	53
Work outside home	11	14	22	27	41	48
Attend church	21	23	12	15	57	67

* ADC = Adult Day Care

** Percentages represent rounding to next highest number.

adult day care, how it may have affected their feelings about and relationship to the older person, and their relationship to other family members. To the question asking primary caretakers what they liked best about the older person's being in adult day care, at least 82% (N=69) responded with such comments as "...she is able to get out with other people and socialize," "...gives her something to look forward to," "...he doesn't drink anymore," or "...don't have to worry about her." Additional comments included, "...he enjoys it," "...he loves it." Several referred to themselves in responding to the question, saying "Gives me time to do things," "...freedom for me from daily responsibility," or "...I can have my home to myself for a few hours." At least two respondents said adult day care made it possible for them to keep the older person at home.

Responses to the question asking primary caretakers how adult day care has affected their relationship to the older person are even more revealing, not only with respect to the very positive effects of the program on their relationship, but also with regard to the tensions and strains involved in having responsibility for the daily care of a physically and/or mentally dependent family member. Responses included, "...It has increased my ability to cope with her," "...it has made it easier to care for her," "...it has made it easier to be patient with her," "...we try harder to be nice to each other," "...she can socialize out there so she's not constantly bugging me--I don't have to be her only friend."

With respect to the latter comment, others conveyed similar feelings, saying, "...it's calmed my nerves so we get along better," "...we are more at ease with each other," "...it has improved our relationship

because it gives me time to myself so that I am not so on edge," "...he is happier, so our relationship is better, " "...my nerves went bad on me before she went--I had to go off and shut the door...now I feel better...I don't walk away." Several respondents referred to the fact that the older person is more interesting as a result of day care, that it gives them more to talk about. One caretaker, whose response while positive was somewhat indifferent, even fatalistic, said, "I appreciate her going, but I don't know that it has made a difference." Only two responses were negative, one respondent saying that because her husband was so unhappy in the program, her relationship to him became worse. Another said that it put distance between them.

With respect to their feelings toward the older person as a result of day care, 54% (N=46) of the respondents said their feelings toward him or her had not changed, one person saying simply, "I just love her," and another also saying, "...I always have had tremendous love and respect for him." In a similar vein another said, "...he couldn't help it. I never felt bad--I have always respected him and have compassion for him." But others who responded to this item indicated that adult day care <u>has</u> made a difference in how they feel about the older person--and all for the better. Such positive effects are illustrated by comments such as, "...he's more important to us now," "...I like him a lot better," "...I like her better as a person--she is more interesting," "...I like her better--she's not so dependent on me," "...it has helped me respect his ability to get out and take care of himself." One person said, "I always used to say, 'I might as well be alone,' but now we talk, he talks to the kids and he has improved so much." The verbal response of one person,

while positive, was more negative in the message it conveyed with respect to her feelings toward the older person, illustrated by her cryptic remark, "It has helped me tolerate her." Another person in a more matter of fact tone said the older person's moving in with the family in the first place was contingent on the availability of adult day care. In other words, had day care not been available, the family probably would have placed the older person in a nursing home.

With respect to other family members, although most respondents, 57% (N=49) indicated adult day care had not affected their relationship to them, others said it had, and again, mostly for the better. Illustrative are such comments as, "...I no longer fly off the handle with them from holding it in with her--I am more relaxed," or "...they've stopped worrying about me." Several referred to the fact that they have more time to be with their families and that they are more relaxed and less tense with them than they were before the older person attended day care. Another reason adult day care seems to have helped to improve family relationships is that primary caretakers no longer had to depend on other family members for help in caring for the older person, several persons commenting they no longer had to ask others to do things for the older person. Thus dependency, whether the older person's or the primary caretaker's on behalf of the older person, seems to have a negative effect on interpersonal relationships, whether between the primary caretaker and other family members or between the primary caretaker and the older person. To the extent day care reduces such dependency, it would seem to be an important factor for improving the quality of family life for families with a disabled older member.

In commenting about the day care programs themselves, many respondents made positive reference to the activities and quality of the programs, the programs' health facilities, and the friendliness and caring qualities of day care staff. Negative comments referred to the cost of adult day care, transportation problems either because the bus sometimes was late, the ride too long, or families were not informed about transportation delays or bus schedule changes. A few commented they wished day care hours were longer and available on weekends. More idiosyncratic comments referred to the adverse effects of adult day care on the person's self image which according to at least two respondents had the unintended consequence of making the older person feel less able to do things for him or herself and more in need of help. One person acidly said, "I do feel they sometimes expect more from the primary caregiver than from the client. They don't encourage enough responsibility on the client's part." One wife said her husband did not like adult day care because he thought she was trying to get rid of him. Nevertheless, despite their latter two negative responses, observations of and reactions to the day care programs and experience were far more positive than negative.

Specific recommendations for improving programs had to do with costs and the public funding of adult day care, the loosening up of hours and schedule where feasible, and making information about day care as a resource for families more widely known. One respondent also suggested that primary caretakers be invited to observe the person in the program on the very first day, adding that counseling should be extended autonomically as a part of the program.

Despite the fact that adult day care has helped most families to perform their functions and cope with their caregiving responsibilites,

most thought they were able to cope and function satisfactorily before the older person participated in day care in each of the specified areas, the only exception being that of working outside the home, 48% (N=41). Indeed, almost all said that before the older person participated in day care, to some extent, a great, and very great extent they were able to: 1) attend to the older person's needs, 92% (N=78); 2) attend to their own needs, 75% (N=64); 3) purchase needed goods and services, 74% (N=63); 4) keep up with household chores, 73% (N=62); 5) attend church, 67% (N=57); 6) do things together as a family and enjoy each other's company as a family, 66% (N=56) each; 7) engage in activities outside the home and be with friends occasionally, 56% (N=47) each; 8) and engage in hobbies they enjoy at home, 52% (N=44) (see Table 8). As one of the respondents indicated, however, before the older person was in adult day care, he or she was not disabled; therefore, before adult day care responses must be interpreted with this possibility in mind. For most, however, the person's disability far preceded his or her participation in adult day care, given that 74% of the older persons had been disabled for far longer than the 2 years determined by the study and 64% had attended adult day care for 2 years or less.

One of the ways, perhaps, such positive before adult day care responses can be understood is that families indeed were able to function and cope effectively with their situation before the older person attended adult day care, until they experienced other stressors or "stress pile-up." Indeed a negative correlation of -.23 between the primary caretaker's ability to cope before adult day care and after the occurrence of stressful family life events gives credence to this possibility. The negative direction of the relationship indicates that the better primary caretakers were able to cope and function

before adult day care, the less effectively they were able to do so following stressful life events of which failing health and serious disability were major components. Thus, it would appear that many of those who functioned well before the older person attended adult day care were unable to cope and function as well as when confronted with stressful family life events. However, it also could be the case that in retrospect, respondents thought they had functioned and coped better before the older person was in adult day care than they actually did, given the effects of time on memory, or that they in fact were high functioning families.

That adult day care was perceived as being extremely helpful to families can be seen by primary caretakers' responses. To the question, "To what extent has adult day care been helpful to you and your family?", a large 86% (N=73) said to a great or very great extent with an additional 11% (N=9) saying to some extent. Only 3 respondents said it helped them to no or only a small extent. Thus, almost everyone considered day care to be very helpful to them. Further, and perhaps most important, most thought it had helped the older person to function better socially, 80% (N=68), physically, 67% (N=56), intellectually, 61% (N=51), and emotionally, 69% (N=59) to some, a great, or very great extent (see Table 9). Illustrative are comments such as, "...he's more alert," "...he talks more," "...he's much better physically and mentally," "...he doesn't feel so sorry for himself now that he sees others in worse shape," "...he interacts more."

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Insert Table 9 about here

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Table 9. Extent to Which Older Person Functions Better Because of Adult Day Care

Older Person's Functioning	No/Small Extent		Some Extent		Great/ Very Great Extent	
	n	%*	n	%	n	%
Socially	17	20	16	19	52	61
Emotionally	26	31	19	22	40	47
Physically	29	34	21	25	35	42
Intellectually	34	40	21	25	30	36

* Percentages may be greater or less than 100 because of rounding.

Most of the older persons, (N=74), meet the costs of adult day care through their own resources, comprised largely of social security and veteran's benefits, to some, a great, or very great extent. For 18% (N=15) of the respondents, such costs were met through the alternative day care grant, Medicare, Medicaid, and private insurance being day care funding sources for only a very few. When asked to what extent day care costs were problematic for them, one-fourth of the primary caretakers, 24%, indicated to some, a great, or very great extent.

Help from Community and Family Resources.

Except for transportation and other miscellaneous services, families of older persons participating in the adult day care programs were not heavy users of community services, although they had used all of the identified services--respite care, homemaker services, counseling, meals on wheels, transportation, nursing services--at least to some extent. Percentages ranged from 5% for meals on wheels to 35% for transportation; only meals on wheels, transportation, nursing and other services were used to a great and very great extent but by only a few. Other resources used by some included home health care, senior companions, and congregate dining.

By and large, family members, particularly spouses and children, were the primary caretaker's major sources of help in caring for the older person. Almost three-fifths, 59% (N=50) said they receive help from family members to some, a great, or very great extent, but interestingly, help from children was so identified by more respondents, 39% (N=33) than help from spouses, 35% (N=29). Other identified sources of family help were siblings, 23% (N=19), friends, 11% (N=9), and other relatives, 9% (N=8) (see Table 10).

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Insert Table 10 about here

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Of all the community services identified as potential family resources, only adult day care was identified by primary caretakers as providing help in caring for the older person to some, a great, and a very great extent, 87% (N=74). Families in the study for the most part did not receive much help from their church or synagogue, public health center, mental health center or county welfare department, such resources being identified as helping to some or a great extent by percentages ranging from 1% for the mental health center to 12% for the public health center (see Table 10). Thus, for the families in this study, adult day care, more than family members and other community resources was a primary resource for helping them with the care of the older disabled person.

Asked to indicate the resources they used for respite care, adult day care again emerged as the primary resource to some, a great, and very great extent for 54% (N=46) of the respondents. Other resources used for respite care were family members, 29% (N=24), hired caretakers, 15% (N=12), and friends, 7% (N=6). Despite its relatively limited use, most respondents, three-fourths, indicated that respite care has helped them to some, a great, and very great extent.

Asked about resources they used for counseling, respondents indicated that to some, a great, and very great extent, they used family members, 55% (N=47), friends, 37% (N=31), their doctor 31% (N=27), and adult day care, 27% (N=23). In general, the families in this study did not use social service agencies, mental health centers, private therapists, or clergy for counseling

Table 10. Extent to which Primary Caretaker Receives Help from Family and Community Resources

Family and Community Resources	No/Small Extent		Some Extent		Great/ Very Great Extent		No Response	
	n	%*	n	%	n	%	n	%
Family Members	32	38	30	35	20	24	3	4
Spouse	19	22	14	17	15	18	37	44
Children	41	48	20	24	13	15	11	13
Siblings	58	69	16	19	3	4	8	9
Other relatives	70	80	7	8	1	1	9	11
Friends	76	90	5	6	4	5	------	
Church/ Synagogue	77	31	4	5	3	4	1	1
Adult Day Care	11	13	27	32	47	55	------	
Public health center	75	90	7	8	3	4	------	
Mental health center	84	99	1	1	------		------	
County welfare Department	79	93	4	5	2	2	------	
Other	47	55	2	2	1	1	35	41

* Percentages may be more or less than 100 because of rounding.

purposes. Again, despite the relatively limited extent to which primary caretakers availed themselves of counseling services, over two-thirds, 67%, indicated it had helped them to some, a great, and very great extent.

Ratings of resources: family, community, and adult day care.

Asked to rate the services they received from family and friends, community agencies, and adult day care (as differentiated from other community resources), in terms of quality, accessibility, availability, reliability, convenience, and cost, except for the latter, respondents rated adult day care services the highest on all of the rated dimensions. Average mean responses ranged on a 5 point scale from 4.1, (s.d.=.85) for cost, to a high of 4.6 (s.d.=.52) for reliability (see Table 11). Services from family and friends also were rated highly on all dimensions, but not as highly as those from adult day care. The one exception was on the dimension of cost on which families and friends received a mean rating of 4.4, (s.d.=.68) in contrast to adult day care's mean rating 4.1, average responses on each of the service dimensions for families and friends ranging from a low of 4.0 for convenience (s.d.=1.0) to a high of 4.4 (s.d.=.68) for quality. For the minority of families using other community services in addition to adult day care, average mean ratings ranged from a low of 3.8 (s.d.=.80) for convenience to a high of 4.3 for quality (s.d.=.49) in contrast to adult day care's rating of 4.5 on the quality dimension as noted above. Such ratings are consistent with responses to open ended questions.

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Insert Table 11 about here

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Table 11. Ratings of Services Provided by Adult Day Care (ADC, N=84) Family and Friends (F&F, N=81) and Other Community Agencies (CA, N=26)*

	Very Poor/Poor						Fair						Good/Excellent					
	ADC		F&F		CA		ADC		F&F		CA		ADC		F&F		CA	
Service Criteria	n	%**	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Quality	------		1	1	------		6	7	6	7	------		79	92	76	88	26	31
Accessibility	4	5	7	8	2	2	6	7	11	13	1	1	75	88	63	74	23	27
Availability	2	2	8	9	3	3	4	5	11	13	3	4	79	93	62	73	20	24
Reliability	------		2	2	1	1	1	1	9	11	2	2	84	99	70	83	23	27
Convenience	2	2	9	11	2	2	3	4	16	19	4	5	80	94	56	66	20	24
Cost	2	2	2	2	------		22	26	3	4	2	2	61	72	75	89	24	29

* No Responses
Adult Day Care, N=1, 1%
Family & Friends, N=4, 5%
Community Agencies, N=59, 69%

** Percentages may not add up to or exceed 100 because of rounding.

Long Term Care for Older Person.

In asking whether or not families had ever used long term care to help them in caring for the older person, 18% (N=15) responded in the affirmative. Primary reasons were the older person's poor functioning, 16% (N=14), and the person's physical needs, 15% (N=13), although 11% indicated their own needs and 5% the needs of other family members, also had played a part in their placement decision. Reasons such as the cost and unavailability of home or adult day care, and the primary caretaker's need to work outside the home played very minimal roles.

The primary reason the older person returned home after placement was that his or her functioning had improved to some, a great, or very great extent, 11% (N=9). Other factors contributing to the person's return included an improved family situation, the availability of adult day care, 3%, and home care, 1%, the improved health of the primary caretaker, 3%, and the availability of a family member who could remain at home with the older person, 4%. These low percentages must be viewed in relation to the 82% who had never placed the older person outside the home in a long term care facility and for whom this set of questions did not apply.

For the present, most families, 93% (N=79) did not plan to place the older person outside the home in a long term care facility. For the 5 who did, health reasons were paramount, the older person's failing health being primary for all 5 respondents, with the health of the primary caretaker and other family members also being considerations, 7%. With respect to the future, however, 46% (N=42) of the respondents indicated they did anticipate placing the older person in a long term care facility with health reasons again being paramount, 44% (N=37) indicating the older person's failing health,

32% (N=27) their own health, and 14% (N=12), the health of other family members as reasons (see Table 12). For 25% (N=21) of the respondents, the unavailability of needed services also was a contributing factor to their long term care plans for the older person. Clearly, for one-fourth of the families, health and service related reasons seem to combine to encourage or necessitate such family planning.

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Insert Table 12 about here

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Influences on the dependent variables.

Which of the variables examined in the study relative to the coping effects of adult day care were influential in this regard? Using Pearson's correlational analysis, the following relationships, all at the .05 significant level or below appeared: the sex of the older person, r=.21, number of sons, r=-.18; the employment status of the primary caretaker, r=.24; annual family income, r=-.23; the alternative care grant, r=.21; the level of older person's impairment, r=.23; and improvement in the older person's functioning, r=.33 (see Table 13). Variables not showing a relationship to the coping effects of the program included: marital status, educational, religious and ethnic background of primary caregiver, living arrangements of older person, number of ways he or she participates in the program, length of time of participation, length of time he or she has been disabled, the occurrence of stressful family life events, county environment, number of daughters and siblings, number of relatives living close by, and health status of primary caregiver and other family members. Conclusions with respect to the non-effects of health status should be held in abeyance, however, since the small numbers of family members and primary caregivers suffering from poor health could

Table 12. Reasons for Planning to Place Older Person in Long Term Care

Reasons	No/Small Extent		Some Extent		Great/ Very Great Extent		No Response	
	n	%*	n	%	n	%	n	%
Older Person's health	2	2	4	5	33	39	46	54
Primary Caretaker's health	12	14	10	12	17	20	46	54
Unavailability of needed ervices	28	22	11	13	10	12	46	54
Other family member's health	27	32	9	11	3	3	46	54

* Percentages may be greater or less than 100 because of rounding.

make such conclusions tenuous at best. Preliminary analysis indicating a negative relationship between the program's coping effects and family health status points to the need for further research in this regard.

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Insert Table 13 about here

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While none of the statistically significant relationships are particularly strong, what they seem to suggest is that adult day care enables primary caretakers and their families to better perform their functions and cope with the care of the disabled older person if the older person is a male whose day care costs are met by the alternative care grant and who, although functionally more impaired, has shown more improvement in his or her functioning as a result of the day care program. Further, the coping effects of day care are more positive if the primary caretaker is not employed, has less income, and fewer sons. Thus, clearly the gender and functioning capacity of the older person, the income status of the primary caretaker, and gender composition of the family are among the determinants of the program's coping effects. In other words, the fewer economic and family resources primary caretakers have available to them and the more disabled the older person is, the greater the program's coping effects. These relationships within the stress framework suggest that day care serves as a greater resource to families in more stressful circumstances in terms of the multiplicity of stressors with which they are are required to cope, as illustrated in this study by the level of the older person's impairment, the primary caretaker's economic status and apparently, gender of the older person and gender distribution of family members.

Table 13. Means and Standard Deviations for Stressful Family Life Events (FLE), Family Coping after Family Life Events (COPE 1), and Help from Family Members (Family Help), by County

	FLE			Cope 1			Family Help		
	$\bar{x}$	s.d.	n	$\bar{x}$	s.d.	n	$\bar{x}$	s.d.	n
Carver	2.39	1.08	24	1.86	.72	23	2.41	.70	26
Hennepin	2.59	1.08	26	2.14	.94	25	1.90	.75	27
Ramsey	3.21	1.17	31	2.44	.92	30	2.22	.84	31
Grand Mean	2.77	1.34		2.18	.89		2.18	.80	

The effects of gender on the program's coping effects are interesting to consider. On the one hand, it would appear that such effects are positive when the older person is male, but negative when there are fewer sons in the family, which, of course, could be a surrogate measure for family size. If that were the case, however, such a relationship also should have appeared for number of children and/or females in the family. Since no such relationship appeared, the program's coping effects indeed seem to be gender related. With regard to the disabled person, it could be the case that males as disabled persons are more difficult for caretakers to manage, thereby increasing the program's coping effects for them. With regard to the negative relationship between number of sons and the program's coping effects, it could be that sons either perform important functions not tapped by the study, or that with each additional son, caretaking burdens are greater, either of which could explain why more sons would decrease the program's coping effects, and alternatively why fewer sons would increase them. Clearly any future research on this topic should clarify the effects of the gender distribution of family members on family coping and functioning.

In addition to the alternative care grant, other resource variables showing a positive relationship to the program's coping effects included counseling received through adult day care, r=.24, counseling received from family members, r=.31, and the rated helpfulness of the counseling, r=.38 (see Table 13). Respite care in the form of adult day care also showed a positive relationship to the program's coping effects, r=.21, as did adult day care's rated helpfulness, r=.45, and the rated helpfulness of services received from other community agencies, r=.22. Thus, counseling, whether through adult day care or from family members, adult day care as respite

care, and the rated helpfulness of both adult day care and services from other community agencies seem to enhance the coping effects of the program with respect to the care of the older person. The relatively strong positive relationship of the rated helpfulness of adult day care to its coping effects should be noted.

In this regard, the positive relationship between the coping effects of adult day care and respondent evaluations of the program in terms of quality, accessibility, availability, convenience, reliability, and cost, r=.43, also should be noted. In conformance with symbolic interaction and expectancy theory, the latter two relationships highlight the interactive effects of perception and affect. That is, the more primary caretakers perceive adult day care as enabling them to cope with their situation, the higher they rated and evaluated the program both in terms of its helpfulness and on established service criteria and vice versa.

With respect to the long term care plans for the older person and its relationship to the program's coping effects, the findings show that the greater the program's coping effects, the more likely it is that primary caretakers anticipated placing the older person in a long term care facility in the future, r=.18. This relationship was further examined in a 2 sample t test which showed that families that anticipate long term care placement for the older person differed significantly from those who did not, t=-2.06, (df=79, sig.=.04) in that the families planning placement experienced the most positive effects from day care. These anomalous findings, however, should be viewed within the context of the positive relationship between the level of the older person's impairment and the caretaker's long term care placement plans for him or her, r=.26. This relationship coupled with the positive relationship

between the older person's level of impairment and the program's coping effects suggests it is the person's level of impairment that probably is the real influencing factor in the family's plans for the person's future long term care in these cases, which helps to explain these seemingly contradictory findings. Thus, regardless of how helpful adult day care may be or how highly it is regarded, or how much it presently enables families to cope with the care of the older person, it cannot be expected to compensate for the older person's declining health and functioning.

With respect to change in families' coping and functioning from before and after the older person attended adult day care, most of the same variables that were influential with respect to the program's coping effects, that is, with respect to families' ability to cope after the older person went into adult day care, not unexpectedly, held for this variable also, and in the same direction. However, some variables showed a relationship to change in family coping as a dependent variable, while not to the coping effects of the program per se. These included: family size, r=.25; ethnicity, r=.29; adult day care costs, r=.19; family coping before adult day care, r=-.68; family coping after adult day care, r=.79, and the older person's improved functioning while in previous long term care, r=-.63 (see Table 13). The small N on which the latter relationship was based, however, (N=14), suggests that this finding should be regarded with caution, but is one that merits further examination in future research on this topic.

With respect to the other variables, however, the findings indicate that larger families, families for whom adult day care costs are a problem, and families in which the older person's functioning improved the least while in previous long term care, tended to experience more positive change in their

functioning and coping capacities following the older person's participation in the program. By the same token, families who functioned and coped well before the older person attended day care showed the least positive change in functioning and coping following the older person's participation in the program. In other words, day care has made the most positive difference in family coping and functioning for families under the greatest stress in terms of the older person's health status, the primary caretaker's financial status, and family size. With respect to family size, it would seem that day care serves to relieve the caretaker of some of the responsibility attendant with simultaneously having to attend to the needs of several children in addition to those of the older disabled person, contradictory to earlier findings with respect to the negative relationship between number of sons and the program's coping effects. Such an anomaly only serves to re-emphasize the need for future research that examines and sorts out the effects of family size and gender distribution on the coping effects of external resources for families.

With respect to the environmental variables of economic well-being of the counties in which families reside and community attitudes toward collective provision, the analysis showed no relationship between these variables and any of the study's dependent variables: the coping effects of adult day care, change in family functioning and coping as a result of adult day care, the rated helpfulness of adult day care, and families' long term care plans for the older person. Nonetheless, an analysis of variance did show these variables to be important relative to stressful family life events, $F=4.13$, ($df=2$, sig.$=.02$); to their effects on family functioning and coping,

not taking day care into account, F=3.04, (df=2, sig.=.05); and to the extent of help primary caretakers received from family members, F=3.02 (df=2, sig.=.05). Such findings suggest that family experience in the 3 counties is different, not only in terms of the occurrence of stressful family life events, but also in terms of family functioning and coping as a consequence of their occurrence, and the help received from family members. Variations in the means for stressful family life events, family coping following stressful life events, and extent of help received from family members in each of the 3 counties may be seen in Table 14.

With regard to family help, it is interesting to note that although the relationship of the primary caregiver to the older person and the older person's living arrangements showed no influence with respect to the study's major dependent variables, they did show an influence with respect to the primary caregiver's receiving from family members: for living arrangements of the older person, Eta^2 = .21 (sig. = 0010), and for relationship of the primary caregiver to the older person, Eta^2 = .22 (sig. = 0006). Spouses living with the older person rated the help they received from family members lower than other primary caregivers.

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Insert Table 14 about here

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Influence of environmental variables on bivariate relationships: coping effects of adult day care and changes in family coping and functioning as a consequence of adult day care.

To further explore their influence, partial correlational analysis was undertaken to control for the influence of each of the environmental vari-

Table 14. Relationship Between Extent to Which ADC enables Families to Cope With Care of Older Person and Other Variables, Controlling for County Economic Well-Being and Attitudes Toward Social Programs*

	Pearson's r	Partial Correlation Coefficient County Economic Well-Being	Partial Correlation Coefficient County Attitudes Toward Social Programs
Sex	.21	.21	ns
Number of sons	-.18	ns**	ns
Caretaker's employment status	.24	.23	.20
Income	-.23	-.23	.20
Alternative care grant	.21	.22	.27
Older person's level of impairment	.23	.23	.21
Improvement in older person's functioning	.33	ns	.34
Long term care plans	.18	--	--
Counseling/ADC	.24	.23	.25
Counseling/family members	.31	.30	.29
Counseling/helpfulness	.38	ns	ns
ADC/respite	.21	.21	ns
ADC/helpfulness	.45	.48	.49
Evaluations/ADC	.43	.45	.44
Evaluations/family	.26	.26	.28

*All reported relationships are statistically significant at the .05 level of probability.

**ns=not significant

ables on statistically significant bivariate relationships. Discussing only those influences that affected the original bivariate relationship, the analysis showed that county economic wellbeing seems to strengthen the relationship between adult day care's coping effects and the alternative care grant, r_{xy}=.22; the rated helpfulness of adult day care, r_{xy}=.48; and caretaker's evaluations of adult day care, r_{xy}=.45, while weakening it slightly for the relationship between the program's coping effects and the primary caretaker's employment status, r_{xy}=.23, adult day care counseling, r_{xy}=.23, and counseling from family members, r_{xy}=.30 (see Table 15).

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Insert Table 15 about here

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County attitudes toward social programs seemed to similarly affect initial bivariate relationships, strengthening it between the program's coping effects and the alternative care grant, r_{xy}=.27, the rated helpfulness of adult day care, r_{xy}=.49, and caretaker's evaluations of the program, r_{xy}=.44 while weakening it between the program's coping effects and the employment status of the primary caretaker, r_{xy}=.20. Variations in the influence of the two environmental variables on the same bivariate relationships should be noted. Of the two, county economic well-being and county attitudes toward social programs, the latter seems to have the stronger influence. Further, county attitudes toward social programs showed an influence on two bivariate relationships which did not surface with respect to county economic well-being: the relationship between the coping effects of adult day care and improvement in the older person's functioning, r_{xy}=.34, and level of older person's impairment, r_{xy}=.21, strengthening the relationship with respect to the first and weakening it with respect to the second.

Table 15. Relationship Between Change in Family Functioning and Coping as a Consequence of Adult Day Care and Independent Variables, Controlling for Economic Well-Being of Counties in Which Families Reside and County Attitudes Toward Social Programs**

	Pearson's r	Partial Correlation County Economic Well-Being	Partial Correlation County Attitudes Toward Social Programs
Sex	.23	.22	.19
Number of children	.25	.26	.25
Employment/primary caretaker	.33	.33	.30
Ethnic background	.29	.29	.31
Income	-.26	-.26	-.26
Older person's level of impairment	.20	.20	ns*
Improvement in older person's functioning	.26	.27	.27
Improvement/older person's functioning while in prior long term care	-.63	ns*	ns*
ADC costs/problem	.19	.19	-.19
Alternative care grant	.19	.19	.25
Counseling/ family member	.19	.19	*
Helpfulness of counseling	.29	*	*
ADC as respite	.28	.28	.23
ADC helpfulness	.28	.30	.32
Evaluation of ADC	.33	.33	.34

*not significant
**all reported relationships are statistically significant at .05 probability level.

Extending the partial correlational analysis to the examination of the influence of county economic well-being on relationships between change in family functioning and coping as a consequence of adult day care and related independent variables, its influence may be seen on the following: sex of the older person, r_{xy}=.22, family size, r_{xy}=.26, adult day care helpfulness, r_{xy}=.30, and improvement in the older person's functioning as a result of adult day care, r_{xy}=.27. However, it did not affect any of the bivariate relationships one way or the other by more than .02, as can be seen on Table 15, in general indicating a slight strengthening of the relationships when taking county economic well-being into account.

The effects of county attitudes toward social programs were more pervasive and stronger than that of county economic well-being, strengthening one relationship between change in family functioning and coping as a result of adult day care by as much as .06, with respect to the alternative care grant, r_{xy}.25, and similarly strengthening it with respect to ethnicity, r_{xy}=.31, perceived helpfulness of adult day care, r_{xy}=.32; caretaker's evaluations of adult day care, r_{xy}=.34; but weakening it with respect to the sex of the older person, r_{xy}=.19, employment status of primary caretaker, r_{xy}=.30, and adult day care as respite care, r_{xy}=.23. Again, variations in the influence of the two environmental variables should be noted. <u>While it is true that none of the partial correlation coefficients dramatically changed the initial bivariate relationships, either with respect to the coping effects of adult day care or change in family coping as a consequence of the program, they do serve to illustrate the need for taking the environment into account in any planned intervention--whether in its design and implementation, or in its evaluation.</u> A comparison

of the influences of each of the environmental variables in Table 15 is suggestive of the different ways in which each works.

Summary and Conclusions

To summarize, adult day care has been very helpful in enabling primary caregivers to cope with the care of the older disabled member. Areas of family functioning most helped by adult day care include attending to the older person's needs, attending to personal needs, keeping up with household chores and enjoying and doing things with family. As a consequence, most respondents thought their relationship to the older person and other family members had improved, reducing tensions created by the older person's total dependency on them and in turn their dependency on family members for helping them with the older person's care. When asked what they liked best about adult day care, respondents specifically mentioned staff friendliness and caring, opportunities of the older person to socialize, and day care health facilities. Specific recommendations for program improvement included extending day care hours, publicizing day care programs, and developing mechanisms for better communicating with families both about program and bus schedule changes. Indeed, transportation was the one component of the day care package about which criticism was expressed.

Almost all respondents thought the program had helped the older person to function better, intellectually, socially, emotionally, and physically. Except for adult day care and transportation, most families participating in the study were not heavy users of community services, family members together with adult day care being the caregiver's major sources of help. Rating of services provided by adult day care, family and friends, and community agencies, based on established service criteria, showed that services provided

by all three sources were highly regarded, but in terms of ranking, those from adult day care ranked highest, family and friends next, and community agencies, third. For some, however, costs associated with day care were a problem.

The coping effects of adult day care were curiously affected by the gender of the older person and the gender distribution of family members. If the older person was male and if the caregiver had fewer sons, the coping effects of the program were greater, suggesting that males either are a greater resource or greater burden for caregivers, thus enhancing or dampening the effects of day care as the case may be. Clearly, the effects of gender as it pertains to males should be clarified in future research with respect to family caregiving of disabled members.

In general, day care is a more important resource for families experiencing the greatest stress, those whose primary caregivers have less money and a mal distribution of males in the family, and those in which the older person is a male who though more severely impaired, has shown the greatest improvement in functioning as a result of participating in the program. The alternative care grant, counseling services and day care as respite care also contribute to the program's positive coping effects.

Environmental variables affected particularly statistically significant bivariate relationships with respect to the coping effects of adult day care and to change in family functioning and coping as a result of the program by as much as .06, strengthening some relationships and weakening others They were particularly influential with respect to family life events, their consequent effects on family coping and functioning, unrelated to day care, and the extent of help families receive from members. These findings suggest that family experience is different for families of disabled older persons

in adult day care in the three counties surveyed. Of the two environmental variables, county economic well-being and attitudes toward social programs, the latter was stronger and more pervasive in its effects. The need to further examine the influence of environmental variables on families' coping and functioning in relation to stressful family life events is readily apparent. Also apparent is the need to take environmental variables into account in planning and developing community resources upon which families can draw to help them in coping with such stressful events. In this regard, the negative relationships between coping responses following stressful family life events, consisting largely of deaths, illnesses and disabilities during the past year, and coping responses before the older person attended day care should be noted. Such analysis suggests that families who functioned well prior to the older person's involvement in adult day care tended not to function as well following stressful family life events, irrespective of day care.

That families and adult day care together may delay but cannot forever prevent the out of home placement of an older person who is severely impaired or whose health is seriously deteriorating is clear from the study's findings. Almost one-half of the families anticipated having to place the older person in a long term care facility, despite the fact that they were the families for whom the coping effects of the program have been the greatest. This must be viewed in the context of the severity of the older person's impairment, however, and caregivers' stated reasons for placement, namely, the older person's failing health.

Given current economic and demographic trends, family caregiving tasks can only grow more difficult in the years to come. Recognition of the importance of the services families provide for their members and indeed

for all of society, calls for policies and programs that support families in their caregiving tasks. For this reason, programs such as adult day care must be viewed in broader context, as programs that although targeted at older disabled persons, have consequences for their families. To maximize their effects, such programs accordingly should be planned from a system's perspective, taking into account not only disabled older persons as their target population, but their families and socio-cultural-economic-political environment as well. Persons concerned about family policy, adult day care being illustrative of indirect and implicit family policy, should carefully monitor the family effects of such programs as they develop and expand under the impetus of the Medicaid waiver and other funding provisions. Observations should focus not only on the extent to which such programs contain the costs of health care, but also on the extent to which they support and maintain individual and family well-being and integrity, or at least do not undermine them. To prevent the latter, observations should be used to trigger discussion about the caring function, how it may be best performed, under what conditions, and by whom, with the respective roles of family, government, and intermediary organizations subject to ongoing redefinition, renegotiation, and readjustment in carrying it out.

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APPENDICES

COMMUNITY SOCIAL SERVICES
Robert A. Sullivan
Director
Phone 448-3661

APPENDIX
A

CARVER COUNTY COURTHOUSE
600 EAST 4TH
CHASKA, MINNESOTA 55318

COUNTY OF CARVER

Carver County Care Center • 401 East Fourth Street • Chaska, Minnesota 55318 • Phone: 448-2136

October 10, 1983

Dear

Carver County Care Center, along with the Adult Daycare Program at Ebenezer in Minneapolis, has been invited to participate in a study of adult daycare and its effects on primary caregivers of elderly persons. This study is being conducted by Dr. Shirley Zimmerman, Associate Professor in the Department of Family Social Service at the University of Minnesota, and it is being funded by the All University Council on Aging at the Uiversity of Minnesota.

The study will be conducted through telephone interviews with the primary caregivers of clients participating in our adult daycare program. Two people have been hired by Dr. Zimmerman to do the telephone surveys; Debra Pearce McCall and Beth Nelson. The interviews will take from one-half hour to 45 minutes to complete, and the calls will be made between 6:30 p.m. and 9:30 p.m. in the evenings, Monday through Friday. If the initial call is made at an inconvenient time for you, you may arrange an interview at some other time. The interviews will be conducted between October 15 and December 15, 1983.

Individual responses will be kept strictly confidential and no respondent will be identified by name in the study's report. I hope all of you will consider this an honor to be asked to be part of this study and that you will all agree to participate. I need to supply Dr. Zimmerman with a list of your names and telephone numbers, and will call all of you this week to get your permission to do so.

Thank you in advance for your anticipated interest, time and cooperation in this effort.

Sincerely,

Meser Henry

Meser Henry

Copy of letter mailed to caregivers

APPENDIX A

EBENEZER

EBENEZER SOCIETY 2523 Portland Avenue, Minneapolis, MN 55404 (612) 871-7112

October 14, 1983

Dear

The University of Minnesota Family Social Science Department is conducting a study to determine the impact that adult daycare has on the family's ability to provide care for a chronically disabled person at home.

Ebenezer's Adult Daycare Program has been asked to participate in this study. Many of the persons who attend adult daycare have family members (spouse, children, nieces, nephews) who provide some primary care that enables that person to maintain their residence in the community.

Your assistance is needed to participate in a telephone interview that will be conducted by a research assistant from the University.

If for any reason you would prefer not to participate in the study please contact Gail Menke or myself at 879-2200, extension 301 by October 21, 1983.

The research assistants who will be conducting interviews are Beth Nelson and Debra Pearce Mc Call.

Thank you for your cooperation and assistance in promoting the adult daycare concept.

Sincerely,

Ann C. Carter

Ann C. Carter
Director
Ebenezer Community Services

APPENDIX A

Amherst H. Wilder Foundation
Since 1906

November 22, 1983

The Wilder Adult Daycare program will be participating in a study to determine the effect of Adult Daycare service on the family of the person participating in the program.

Dr. Shirley Zimmerman from the University of Minnesota is directing the survey. An appointment will be made in advance to conduct the telephone interview in the evening. The interview will take about 30 - 40 minutes.

We have suggested that you might be willing to participate in the survey. Such a decision is of course voluntary and any information you share will be confidential.

We feel that this type of study will give us some very valuable information about the benefits of Adult Daycare as well as areas where we might be able to improve our service.

Beth Nelson and Debra Pearce McCall are the interviewers working with Dr. Zimmerman. One of them will be calling you soon. Although we have made an introductory call to prepare you for this letter, Please do not hesitate to call us if you have any questions.

Sincerely,

Dorothy W. Ohnsorg
Director

DWO/blm

Division of
Services to the Elderly
Adult Daycare Center
516 Humboldt Avenue
St. Paul, MN 55107
(612) 291-8030

APPENDIX B

ADULT DAY CARE: ITS EFFECTS ON FAMILIES OF PRIMARY CAREGIVERS OF ELDERLY DISABLED PERSONS

ID# _____ Date _____ Name _____
1-2-3

Name of Adult Day Care Participant _____

Interviewer's Name _____

Interviewers: After introducing yourself to the person who assumes the most responsibility for the elderly disabled person in adult day care, explain the purpose of the study, and in general, follow the instructions on the attached sheet. Always refer to the elderly disabled person by name.

Please Note: Place the actual number, or where coded responses are given, the coded number of the most appropriate response in the numbered space beside each item. For items for which no coded response appears on the questionnaire, write in actual response in the unnumbered space next to the item. After completing the interview, refer to the code sheet with the numbered coded responses and place the number that matches the response for that item in the numbered space beside it. If the item is not applicable to the person, code the response a 9 unless otherwise indicated.

4. _____ Relationship to elderly person in adult day care _____ (see code sheet)

5-6. _____ Age

7-8. _____ Age of disabled elderly person

9. _____ Sex of disabled elderly person Code: 1) female 2) male

10. _____ Marital status Code: 1) married 3) divorced or separated 5) never married
2) remarried 4) widowed

11-12. _____ Number of children in the family

13-14. _____ Number of children living at home

15-16. _____ Number of other relatives living in the home

17-18. _____ Number of non-relatives living in the home

19-20. _____ Number of daughters

21-22. _____ Number of sons

23-24. _____ Number of sisters

25-26. _____ Number of brothers

27-28. _____ Number of family members living within a half hour's drive

29-30. _____ Age of oldest child

31-32. _____ Age of youngest child

33. _____ Employment status Code: 1) full time 2) part time 3) unemployed

34. _____ Educational background Code: 1) less than high school 4) college graduate
2) high school 5) post graduate education
3) some college

35. _____ Ethnic background Code: 1) white 3) Native American 5) Oriental
2) black 4) Hispanic 6) other, what? _____

36. _____ Religious preference Code: 1) Protestant 3) Jewish
2) Catholic 4) other, what? _____

37. _____ Annual family income _____ (see code sheet)

38. _____ Living arrangements of elderly disabled person _____ (see code sheet)

Extent to which health status or disability of older person in adult day care affects his or her ability to: Code: 1) to absolutely no extent 4) to a great extent
2) to a small extent 5) to a very great extent
3) to some extent

39. _____ see
40. _____ walk
41. _____ talk
42. _____ hear
43. _____ feed self
44. _____ toilet self
45. _____ relate to people
46. _____ communicate with people
47. _____ understand what is said to him or her

48. _____ Length of time member has been incapacitated _____ (see code sheet)

49. _____ Health status of other family members for whose care you are responsible
Code: 1) very poor 3) fair 5) excellent
2) poor 4) good

If less than good, to what extent does that member's health stauts or disability affect his or her ability to: Code: See code for items 39-47.

50. _____ see
51. _____ walk
52. _____ talk
53. _____ hear
54. _____ feed self
55. _____ toilet self
56. _____ relate to people
57. _____ communicate with people
58. _____ understand what is said to him or her

59. _____ Your health status Code: See code for item 49.

60. _____ If less than good, to what extent does your health status affect your ability to care for disabled older person? Code: See code for items 39-47.

61. _____ Who in the family in addition to you assumes most responsibility for the care of the the disabled older person? _____ (see code sheet)

62. _____ Is that member the oldest child in the family? Code: 1) yes 0) no

63. _____ Who in the family assumes the least responsibility for the care of the disabled older person? _____ (see code sheet)

64. _____ Is that member the youngest child in the family? Code: 1) yes 0) no

To what extent have any of the following events been a source of stress for you or your family this past year? Code: See code for items 39-47.

65. _____ death of a family member
66. _____ serious illness of a family member
67. _____ loss of a job
68. _____ divorce or separation
69. _____ addition of new family member through birth
70. _____ addition of new family member through adoption
71. _____ addition of new family member through marriage or remarriage
72. _____ job change
73. _____ serious disability
74. _____ large loss of income
75. _____ large increase in income
76. _____ difficulty with the law
77. _____ institutionalization of a family member

To what extent have any of these experiences affected your or your family's ability to:

78. _____ keep up with household chores Code: See code for items 39-47.
79. _____ purchase goods or services needed
80. _____ work outside the home

Card 2
1

5. _____ do things with each other as a family
6. _____ enjoy each other's company as a family

ID#
2-3-4

7. _____ engage in hobbies you enjoy at home
8. _____ engage in leisure time activities outside the home, such as going to movies, walking, etc.
9. _____ be with friends occasionally
10. _____ attend church or synagogue
11. _____ attend to needs of elderly disabled person
12. _____ attend to your own individual needs
13. _____ attend to needs of other family members

To what extent has adult day care helped you and your family to:

14. _____ keep up with household chores Code: See code for items 39-47.
15. _____ purchase goods or services needed
16. _____ work outside the home
17. _____ do things with each other as a family
18. _____ enjoy each other's company as a family
19. _____ engage in hobbies you enjoy at home
20. _____ engage in leisure time activities outside the home, such as going to movies, walking, etc.
21. _____ be with friends occasionally
22. _____ attend church or synagogue
23. _____ attend to needs of elderly disabled person
24. _____ attend to your own individual needs
25. _____ attend to needs of other family members

Before elderly disabled member was in adult day care, to what extent were you able to:

26. _____ keep up with household chores Code: See code for items 39-47.
27. _____ purchase goods or services needed
28. _____ work outside the home
29. _____ do things with each other as a family
30. _____ enjoy each other's company as a family
31. _____ engage in hobbies you enjoy at home
32. _____ engage in leisure time activities outside the home, such as goind to movies, walking, etc.
33. _____ be with friends occasionally
34. _____ attend church or synagogue
35. _____ attend to needs of elderly disabled person
36. _____ attend to your own individual needs
37. _____ attend to needs of other family members

38. _____ To what extent are the costs associated with adult day care for the disabled elderly person a problem for your family? Code: See code for items 39-47.

To what extent are the costs associated with adult day care covered by:

39. _____ your own insurance Code: See code for items 39-47.
40. _____ medicaid
41. _____ medicare
42. _____ Title XX funds
43. _____ a special grant from the state
44. _____ your own savings or earnings

To what extent does your family use any of the following services in addition to adult day care for the elderly disabled person? Code: See code for items 39-47.

45. _____ respite care
46. _____ homemaker services
47. _____ counseling
48. _____ meals on wheels
49. _____ transportation for handicapped persons
50. _____ nursing services
51. _____ other, what? _____

To what extent do you receive help in caring for the disabled older person from:

52. _____ family members Code: See code for items 39-47.
53. _____ spouse
54. _____ adult children
55. _____ siblings
56. _____ other relatives
57. _____ friends
58. _____ church or synagogue
59. _____ adult day care center
60. _____ public health center
61 _____ mental health center
62. _____ county welfare department
63. _____ other community agencies, what? _____

Overall, how would you rate the services the older disabled person receives through adult day care in terms of: Code: 1) very poor 2) poor 3) fair 4) good 5) very good

64. _____ quality
65. _____ accessibility
66. _____ availability
67. _____ reliability
68. _____ convenience
69. _____ cost

Overall, how would you rate the services the older disabled person receives from family and friends in terms of: Code: See code for items 64-69.

70. _____ quality
71. _____ accessibility
72. _____ availability
73. _____ reliability
74. _____ convenience
75. _____ cost

Card 3
1

ID# _____
2-3-4-

Overall, how would you rate the services the older disabled person receives through such community agencies as the county welfare department or the public health department in terms of: Code: See code for items 64-69.

76. _____ quality
77. _____ accessibility
78. _____ availability
79. _____ reliability
80. _____ convenience
5. _____ cost

To what extent do you or have you used any of the following resources for counseling in relation to the elderly disabled person? Code: See code for items 39-47.

6. _____ social service agency
7. _____ mental health center
8. _____ adult day care center
9. _____ private therapist
10. _____ doctor
11. _____ clergy
12. _____ friend
13. _____ other family member

14. _____ To what extent has such counseling been helpful to you? Code: See code for items 39-47.

To what extent do you or have you used any of the following resources for respite care in relation to elderly disabled person? Code: See code for items 39-47

15. _____ state hospital
16. _____ foster home
17. _____ adult day care
18. _____ other family members
19. _____ friends
20. _____ hired baby sitter
21. _____ other, who or what? _____

22. _____ To what extent has such respite care been helpful to you? Code: See code for items 39-47.

23. _____ Have you ever placed the elderly disabled person out of the home in a long term care facility? Code: 1) yes 0) no

If yes, to what extent did any of the following reasons contribute to your decision to do so? Code: See code for items 39-47

24. _____ person's poor functioning
25. _____ needs of other family members
26. _____ your own needs, health or other
27. _____ costs of in home care
28. _____ need to work outside the home
29. _____ unavailability of home care
30. _____ unavailability of adult day care
31. _____ needs of elderly disabled person

To what extent did any of the following reasons contribute to the family's decision to have the elderly disabled person return home? Code: See code for items 39-47

32. _____ person's functioning improved
33. _____ family situation improved
34. _____ adult day care became available
35. _____ home care services became available
36. _____ ways of paying for adult day care became available
37. _____ ways of paying for home care services became available
38. _____ you or another family member were able to remain at home
39. _____ your health improved

40. _____ Do you presently have plans to place the disabled older person out of the home in a long term care facility? Code: 1) yes 0) no

If yes, to what extent do the following reasons contribute to your plans?

41. _____ older person's failing health Code: See code for items 39-47.
42. _____ your health
43. _____ health of other family members
44. _____ other, what? _____

Do you anticipate having plans to place the disabled older person out of the home in a

45. _____ long term care facility? Code: 0) no 1) depends 2) yes

If yes, to what extent would any of the following reasons contribute to your plans?

46. _____ older person's failing health Code: See code for items 39-47.
47. _____ your health
48. _____ health of other family members
49. _____ unavailability of needed services, such as adult day care
50. _____ other, what? _____

51. _____ To what extent has adult day care for the elderly disabled person been helpful to you and your family? Code: See code for items 39-47.

To what extent do you think the elderly disabled person has functioned better than what you might have expected without the adult day care program . . Code: See code for items 39-47.

52. _____ socially
53. _____ physically
54. _____ intellectually
55. _____ emotionally

56. _____ How did you first learn about the adult day care program?

Code: 1) social worker
2) friend
3) family member
4) newspaper article
5) families of other program participants
6) family doctor
7) minister or rabbi
8) other, who or what? _____

Go on to next page.

1. What do you like best about adult day care with respect to the elderly disabled person?

2. What do you like least about adult day care with respect to the elderly disabled person?

3. How has adult day care affected your relationship to the older disabled person?

4. How has adult day care affected the way you feel about the older disabled person?

5. How has adult day care affected your relationship to other family members?

6. Other comments or suggestions?

Thank you very much for your time.

Information to be obtained from public records.

Name _____

ID# _____

57. _____ county of residence

58. _____ county in which adult day care program is located

59. _____ county population

60. _____ county per capitata income

61. _____ county per capita expenditures for social service programs for older persons

62-63. _____ length of time person has participated in the adult day care program (in months)

64. _____ number of days per week person participates in adult day care program

65. _____ auspices of adult day care program

CODE

Card 1 Items 4, 61, and 63

o) no one
1) wife
2) husband
3) daughter
4) son or daughter-in-law
5) sister
6) brother or sister-in-law
7) parent
8) other relatives, i.e., niece, grandniece, grandson

Item 37

1) $5,000 or less
2) $5,000 to $9,000
3) $10,000 to $14,000
4) $15,000 to $19,000
5) $20,000 to $24,000
6) $25,000 to $29,000
7) $30,000 to $39,000
8) $40,000 to $49,000
9) $50,000 or more

Item 38

1) lives alone
2) lives with spouse
3) lives with adult daughter
4) lives with adult son
5) lives with spouse and children
6) lives with friend
7) lives with paid caretaker
8) lives with other relatives, not spouse or children
9) other, what?

Item 48

1) four months or less
2) four to six months
3) six to eleven months
4) twelve to seventeen months
5) a year and a half to two years
6) two years or more

Card 3 Item 45

code should read:
0) no
1) depends
2) yes

CODE

Items 57 and 58

1) Carver
2) Hennepin
3) Ramsey

Item 59

1) Carver	39,165
2) Ramsey	458,368
3) Hennepin	946,401

Item 60, 1981

1) Carver	$ 9,546
2) Ramsey	12,493
3) Hennepin	13,801

Item 61, 1981

1) Carver	$ 25.07
2) Hennepin	27.12
3) Ramsey	31.28

Item 62, in months

Item 64, actual number

Item 65

1) Public	Carver
2) Private/Sectarian	Hennepin
3) Private/Non-Sect.	Ramsey

APPENDIX C

ADULT DAY CARE: ITS EFFECTS ON PRIMARY CAREGIVERS OF ELDERLY DISABLED PERSONS AND THEIR FAMILIES

INTERVIEWER INSTRUCTIONS

Objectives of the Study

This study is being conducted to examine the effects of adult day care on families and primary caregivers of elderly disabled persons participating in adult day care programs in selected sites throughout the state. The study is being conducted to obtain information that will lead to a better understanding of primary caregivers and families of such members and the role that adult day care may play in alleviating some of the stress they may experience as a consequence of having a disabled family member for whose care they are responsible.

Primary Investigator

The primary investigator for the study is Shirley Zimmerman, Ph.D., Associate Professor, Family Social Science, University pf Minnesota.

Procedures

The persons you will be interviewing are the primary caregivers of an elderly disabled person in an adult day care program. Primary caregivers may or may not be living with the elderly person, but they are the family member or person most responsible for the older person's care. All potential interviewees will have received a letter from the director of the adult day care program in which the older person is participating, alerting them to the study and enlisting their cooperation in it.

All initial contacts with primary caregivers should be made between 6:30 and 9:30 in the evening.

Before proceeding, it is important to obtain the person's verbal permission to be interviewed. Begin by introducing yourself, explaining your connection to the study and the study's purpose. Inform the person that his or her responses will be keptstrictly confidential and that no one will be identified by name in the study's report.

Also inform the person that the interview will take no more than one-half hour to 45 minutes to complete, but that it could take less time too.

If the person agrees to participate, inform him or her that he or she will receive a summary of the study's findings if he or she is interested in receiving a summary. Be sure to make a notation of those who would like a summary by writing the word "summary" after his or her name on the attached list.

If the person agrees to participate in the study but says the timing of your call is inconvenient for an interview then, arrange to call back at another mutually agreed upon time.

If the person does not wish to participate in the study, terminate the conversation courteously. However, note the person's decision by writing a "no" after the person's name on the attached list. Such a notation is for record keeping purposes for the study only.

If the person expresses a concern about the older person's program status if he or she does not wish to participate in the study, assure him or her that the older person's program status will in no way be affected by the decision.

Always use the older person's actual name when referring to him or her throughout the interview in place of the wording that appears in the questionnaire with reference to the older person.

If an item or set of items does not apply to the person's situation, go on the the next set of questions. Unless otherwise indicated, code items a 9 when questions are not applicable. All numbered spaces should be filled with a code number by the time the interview has been completed.

Open ended questions at the end of the questionnaire are not to be coded. Be succinct in the recording of responses, getting their essence, not their elaborations.

Be friendly and put the person at ease. The ease with which you conduct the interview will depend on your familiarity with the questionnaire and the study's purposes. Be brief. No interview should take more than a half hour to 45 minutes to complete.

Please note: Although this is a structured questionnaire, it is meant to be used in the manner of an interview guide. Therefore, it should not be necessary to read all of the coded scaled responses for each item on which information is being sought. Very often respondents will provide the information you want without your having to repeat the coded scales each time, although you may have to guide them in their responses to be consistent with the scales and the framework of the study. Follow coding instructions throughout.

If you have any questions please call me immediately: 376-5694, office; 926-8644, home; 373-1578, FSS main office; and 373-5831, CESW office. You can leave messages for me at the latter two numbers andd I will return your call.

You should be able to complete 8 to 12 interviews per week. Return completed questionnaires to me weekly until you have completed all the interviews on the list or have accounted for the non-interviews.

APPENDIX D

ORAL CONSENT

Hello, this is _____. A few weeks ago you received a letter from the Director of the Adult Day Care Program at Ebenezer Society with regard to a study that is being conducted concerning the effects of adult day care on primary caregivers and families of elderly disabled persons participating in adult day care programs. The study is being conducted by Shirley Zimmerman who is with the Department of Family Social Science at the University of Minnesota.

I am calling to find out if you would like to participate in the study, and if so, if this is a good time for us to talk. If it is not a good time to talk, then perhaps we can make an appointment for a better time for you. We will need 30 to 45 minutes to complete the interview and you do not have to answer any questions that you may find uncomfortable. Again, just to repeat, all your answers will be kept strictly confidential, and if you wold like a summary of the study findings, we will be happy to send you one when the project has been completed. We are hoping the findings will help to contribute to better policies and programs with respect to community and home care of elderly disabled persons. By participating in the study, you will be helping to do that. Before we begin, though, do you have any questions you would like to ask about the study. Please feel free to interrupt at any time during the interview if you have questions you would like to ask.

. . . . . .

If the person says he or she would <u>not</u> like to participate in the study and does not wish to be bothered, the interviewer will say after the fist sentence in the second paragraph:

Thank you very much for your time and interest anyway. Do you have any questions you would like to ask about the study? If you should change your mind and decide you would like to participate in it after all -- before the interview period is over - let me give you my name again and phone number so that you can reach me.

Thank you again.